




angelman
SYNDROME FOUNDATION

CHAMPIONING PROGRESS

BIENNIAL CONFERENCE AND SCIENTIFIC SYMPOSIUM

JULY 23 – JULY 26, 2013 • WALT DISNEY WORLD SWAN & DOLPHIN • ORLANDO, FL



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Championing Progress • July 23 – July 26, 2013
Walt Disney World Swan & Dolphin • Orlando, FL

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2013 ASF BIENNIAL CONFERENCE ORGANIZING COMMITTEE

Scientific Symposium Program Co-Chair
Dr. Michael Greenberg

Scientific Symposium Program Co-Chair
Dr. Ben Philpot

Scientific Symposium Program Co-Chair
Dr. Charles Williams

Scientific Symposium Program Co-Chair
Lisa Franco

Scientific Symposium Program Co-Chair
Dr. Dan Harvey

ASF Conference Coordinator
Sheila Wenger

ASF Executive Director
Eileen Braun

WHO SHOULD ATTEND?

- Families of individuals with AS
- Researchers
- Physicians
- Educational Professionals
- Occupational Therapists
- Physical Therapists
- Speech & Language Pathologists
- Care Providers
- Anyone interested in improving the lives of individuals with AS and their families

The ASF's 13th Biennial Conference has something for everyone, whether you are a first-timer or have attended previous conferences; whether your individual with AS is older or younger; if you are involved in the day-to-day care of an individual with AS, or are a professional working with students, patients or families affected by AS. Nearly 40 sessions have been scheduled to provide a diverse program for all attendees.

QUICK CONTACT INFORMATION

Angelman Syndrome Foundation
4255 Westbrook Drive, Suite 219
Aurora, IL 60504
800-432-6435
International: 630-978-4245
Fax: 630-978-7408
Email: info@angelman.org
www.angelman.org

Walt Disney World Swan & Dolphin
Conference held at the Swan
1500 Epcot Resorts Blvd.
Lake Buena Vista, FL 32830
800-227-1500

Register online at www.angelman.org!

WELCOME

Championing Progress • July 23 – July 26, 2013
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Championing Progress is the theme for the 2013 Angelman Syndrome Foundation Biennial Conference, for several reasons. Since the last Conference in 2011, many new developments have occurred in the world of Angelman syndrome and at the ASF, and together we are making great progress—and the Conference is the optimal time for you to learn more about how these developments can positively impact the life of your loved one with AS.

During the past two years, research has made significant headway in further understanding the genetic complexities of AS and in advancing treatments for symptoms. We now know the possible underlying cause of seizures in AS and developed an effective dietary treatment for reducing seizures. A research team at University of North Carolina also discovered a possible treatment for AS overall by successfully administering an already FDA-approved drug in AS mouse models. Numerous research projects funded by the ASF are ongoing and are making tremendous progress, and we are proud to continue to champion these on behalf of all individuals with AS. Select researchers and medical professionals dedicated to advancing this research will be at this year's Conference and welcome the opportunity to speak with you. A cure is waiting in the wings!

At this year's conference, we are pleased to welcome keynote speakers who are going to be addressing two very important topics, one of them being Dr. Stephen Calculator who will discuss how to better foster communication in individuals with AS. This session will review communication characteristics associated with AS and then discuss the techniques and strategies that have been found useful in enhancing individuals' communication skills. Along those same lines, Dr. Jane Summers will discuss the ASF's recently launched Series on Angelman Syndrome Behaviors. These behavioral modules were created to help parents, educators and caregivers of individuals with AS to understand the causes of challenging behavior and recommend practical interventions for them, and Dr. Summers will discuss how to get the most out of the Series on Angelman Syndrome Behaviors.

In addition, the ASF is honored to host a variety of other breakout sessions, including those with speakers and others designed specifically for collaboration among attendees. A couple sessions will focus on additional communication topics related to AS, including a session about changing platforms of Alternative and Augmentative Communication (AAC) devices for individuals with AS. Dr. Ron Thibert will present his research about seizures and the low-glycemic index treatment (LGIT) for seizures in individuals with AS, and in another similar session, Sybille Kraft-Bellamy, a parent of an individual with AS, will discuss her experiences with implementing the LGIT. Another important session to attend is one hosted by Dr. Judith Coucouvanis, during which she will discuss strategies for success in toilet training individuals with AS. A number of additional sessions will round out this year's Conference and provide you with valuable information as you progress on your journey with Angelman syndrome.

Finally, perhaps one of the most important reasons to attend the Conference is the opportunity to spend time with other families of individuals with AS from around the country to share experiences, best practices and just enjoy each other's company as you together embrace your loved ones with AS. The Conference is about learning and growing and supporting each other, and we at the ASF are honored to be a part of your journey with Angelman syndrome. Together, we are Championing Progress towards a cure and an even better quality-of-life for individuals with Angelman syndrome.

We look forward to seeing you in Orlando!

Sheila Wenger
ASF Conference Coordinator

CONFERENCE FINANCIAL ASSISTANCE

Championing Progress • July 23 – July 26, 2013

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CONFERENCE FINANCIAL ASSISTANCE

Costs associated with traveling to Orlando and attending the conference can seem daunting for some families and formidable for others. Fortunately, financial assistance may be available through your own community networks and agencies. Many community services provide financial assistance to families who have children with disabilities. The organizations in your area recognize the importance of conferences such as these in order to promote inclusion in our society, as well as providing strong support systems for families who have children with disabilities. Here are just a few organizations that may be able to provide assistance to those who would like to attend the conference:

1. ASF – There is limited funding set aside for scholarship assistance. An application is available on pages 14 - 15.
2. The National Dissemination Center for Children with Disabilities is a federally funded program that serves as a central source of information on resources available to individuals with disabilities. Go to www.angelman.org and click on Resources and then State Resources. Click on your state on the map.
3. Each state also has a Developmental Disabilities Council (DDC), <http://www.nacdd.org>, which is a planning and advocacy body that is committed to community inclusion for people with developmental disabilities. You must submit a proposal (a one to two page letter) explaining how the event promotes the principles of DDC and how it will benefit families. Remember to use broad terms when you submit your letter such as inclusion, future's planning, family supports topics, and networking. Discuss long-term care supports such as waivers, Social Security, and other types of supports such as Children's Health Care Plans (CHIP). Please share with the DDC how you plan to share this information with your networks when you get back home. Tell them that you will share it with the education systems, other parents (not just parents raising children with AS).
4. Many local community clubs provide sponsorships to families. These clubs include, but are not limited to: Optimist and Soroptimist, Lions, Moose Family Fraternities, Kiwanis, Rotary, Junior Leagues, Knights of Columbus, Mason's, and Eastern Star. Don't forget VFW's and American Legions for military families.
5. You may wish to contact your University Center for Excellence and Protection and Advocacy groups (also found under state resources on the NICHCY webpage). Often these groups will have a fund to provide family support and education through conferences. These two organizations are sister organizations of the DDC and are required to help families through multiple efforts.
6. Contact your local Parent-To-Parent organization and ask them if they know of any support networks that will assist in the conference. You may also try the following local providers in your area:

- Frequently Councils for Developmental Disabilities provide funding for families to attend conferences. This varies from state to state. To get information, Google the phrase Developmental Disabilities Council and the name of your state and give them a call. For example, The Arc of Illinois, through a grant from the Illinois Council on Developmental Disabilities, administers the Consumer Involvement Program and distributes consumer stipend funds to enable people with developmental disabilities and their family members to attend conferences of their choice that are directly related to developmental disability issues. <http://www.thearcofil.org/consumer-stipend-project>. For a complete list of the various councils for each state, please visit [insert webpage]
- Family Cafe (Florida) Consumers and Families Leadership and Development Assistance Program provides assistance to attend conferences and training. <http://www.familycafe.net/>
- Family Involvement Fund (Indiana residents only) provides financial support for family members of children with disabilities to help increase knowledge and understanding of their child's disability and/or the systems that provide services. For more information please contact:
C/O Family Involvement Fund
2853 E. 10th Street, Bloomington, IN 47408
1-800-825-4733 (Indiana only); 1-812-855-6508
Fax: 1-812-855-9630; Email: fif@indiana.edu
Questions: Ask for Cathy Beard or Sharon Hauss
- Canyon Rice Hope Scholarship offers grants, to children with developmental disabilities, items not covered by insurance or waivers. There are two main types of grants currently available: grants for caregiver supports and grants for therapeutic items. If you wish to apply for a grant or would like more information, please contact jenny_L_rice@yahoo.com.
- United Cerebral Palsy: Contact your local UCP affiliate to find family support information and resources. If there is no affiliate in your area, please call 800-872-5827 or send email to info@ucp.org or via internet at <http://www.ucp.org/resources/parents-and-families>.
- Children's Charity Fund provides services and purchases medical equipment for handicapped and disabled children, and provides educational grants to help children further their education. <http://childrenscharityfund.org/>
- Easter Seals provides services to help children and adults with disabilities and/or special needs as well as support to their families. <http://www.easterseals.com>

The best way to find out if an organization will sponsor a conference is to network, network and network. And don't be afraid to ask!

SPONSORSHIP OPPORTUNITIES

Championing Progress • July 23 – July 26, 2013

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Option 1: Opening Reception	\$10,000	Diamond Sponsor
<p>The opening reception creates a very special welcome to the families and a meaningful introduction to the conference. This event is the first time for many families to catch up with old friends and for new families to meet others who have experience with Angelman Syndrome. As attendees meet and network, it is the first opportunity for a sponsor to reach a majority of the conference audience.</p>		
Option 2: Children's Program	\$10,000	Diamond Sponsor
<p>While parents are in seminars during conference sessions, on-site activities and off-site activities, snacks and lunches are provided for the children and their caregivers.</p>		
Option 3: Audio Visual Equipment	\$10,000	Diamond Sponsor
<p>One of the most expensive costs of the conference is audio visual equipment. This equipment ensures that presentations to all attendees are at the highest standard.</p>		
Option 4: Conference Program Book	\$10,000	Diamond Sponsor
<p>The conference program book is provided to all registered conference attendees and contains speaker contact information, presentation handouts, listing of sponsors and general conference information.</p>		
Option 5: Conference Bags	\$5,000	Platinum Sponsor
<p>All attendees will receive a bag to carry their education materials throughout the conference. Your company's name and logo will be placed on one side of the bag and the ASF logo will be placed on the other.</p>		
Option 6: Transportation	\$5,000	Platinum Sponsor
<p>Coach buses will be provided to transport children and their caregivers to off-site activities. Your company's name and logo will be displayed on each coach and provides great exposure, not only to conference attendees, but to the general public as well.</p>		
Option 7: Scientific Reception	\$5,000	Platinum Sponsor
<p>This reception will be a capstone to the first full day of scientific sessions and will allow our esteemed scientific speakers and attendees to network among their peers.</p>		
Option 8: Scientific Luncheon	\$5,000 each	Platinum or Diamond Sponsor
<p>The highlight of a special day centered around leading authorities on Angelman Syndrome and attendees, this luncheon is an opportunity to reach out to the professional scientific community.</p>		
Option 9: Breakfast Host	\$5,000 each	Platinum or Diamond Sponsor
<p>Be noticed by speakers and attendees first thing in the morning by hosting one of the most important meals of the day. Help energize attendees and get them ready for the day by sponsoring one or all of the breakfasts (Thursday, Friday & Saturday).</p>		
Option 10: Keynote Speaker/General Sessions	\$2,500	Gold or Platinum Sponsor
<p>General Sessions provide opportunities for all attendees to gather and hear from invited speakers on topics of broad interest. The conference will feature two (2) keynote speakers/general sessions. Your help to underwrite the cost of each of these outstanding speakers will be recognized during the keynote session, in addition to recognition on conference signage.</p>		
Option 11: Family Sponsor	\$1,000	Silver Sponsor
<p>The conference registration and hotel costs associated with attending a conference often prevent families from participating. Consider helping an AS family experience the educational and networking benefits of attending an AS conference.</p>		
Option 12: Lanyards	\$1,000	Silver Sponsor
<p>Lanyards are offered to all attendees to be worn around the neck to hold their name badges. Your organization's name will appear on the lanyards.</p>		
Option 13: Disney Character(s)	\$1,000	Silver Sponsor
<p>You have the unique, memorable opportunity to sponsor one, or all, of four Disney Character appearances. Each appearance, lasting 30 minutes, cost \$1,000. It's a great way to create a magical experience for children (and their parents!).</p>		
Option 14: Coffee Breaks	\$500 each	Bronze, Silver or Gold Sponsor
<p>Attendee breaks are offered at various times throughout the conference. Take this opportunity to sponsor one or more of the four (4) breaks and provide attendees with much needed refreshment! Your name and logo will be what everyone sees as they mingle around the break stations.</p>		
Option 15: Daily Newsletter	\$200 each day	Bronze Sponsor
<p>Printed daily throughout the conference and designed to enhance attendees' conference experience, the Daily Conference Newsletter includes session and attendee updates and highlights of the day's activities. Sponsorship entitles your company to placement of your name and logo on the front cover of each newsletter to capture the attention of our conference-wide audience (Wednesday, Thursday, Friday & Saturday).</p>		

SPONSORSHIP/VIRTUAL EXHIBITOR REGISTRATION FORM

Championing Progress • July 23 – July 26, 2013

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First Name _____ Last Name _____

Company Name _____

Address _____

City _____ ST/Province _____ Zip/Postal Code _____

Country _____ Phone _____

Email _____

INDICATE YOUR SPONSORSHIP OPTIONS:

Sponsorable Opportunity

Amount

Dollar Support

- | | | |
|---|--------------|----------|
| <input type="checkbox"/> 1. Opening Reception | \$10,000 | \$ _____ |
| <input type="checkbox"/> 2. Children's Programs | \$10,000 | \$ _____ |
| <input type="checkbox"/> 3. Audio Visual Equipment | \$10,000 | \$ _____ |
| <input type="checkbox"/> 4. Conference Program Book | \$10,000 | \$ _____ |
| <input type="checkbox"/> 5. Conference Bags | \$5,000 | \$ _____ |
| <input type="checkbox"/> 6. Transportation | \$5,000 | \$ _____ |
| <input type="checkbox"/> 7. Scientific Reception | \$5,000 | \$ _____ |
| <input type="checkbox"/> 8. Scientific Luncheon(s) | \$5,000 each | \$ _____ |
| <input type="checkbox"/> 9. Breakfast Host | \$5,000 each | \$ _____ |
| <input type="checkbox"/> 10. Keynote Speaker/General Sessions | \$2,500 each | \$ _____ |
| <input type="checkbox"/> 11. Family Sponsor | \$1,000 | \$ _____ |
| <input type="checkbox"/> 12. Lanyards | \$1,000 | \$ _____ |
| <input type="checkbox"/> 13. Disney Character(s) | \$1,000 | \$ _____ |
| <input type="checkbox"/> 14. Coffee Breaks | \$500 each | \$ _____ |
| <input type="checkbox"/> 15. Daily Newsletter | \$200 each | \$ _____ |

General Conference Sponsorship

- | | | |
|---|-------------------|----------|
| <input type="checkbox"/> 16. Diamond Sponsor | \$10,000+ | \$ _____ |
| <input type="checkbox"/> 17. Platinum Sponsor | \$5,000 – \$9,999 | \$ _____ |
| <input type="checkbox"/> 18. Gold Sponsor | \$2,500 – \$4,999 | \$ _____ |
| <input type="checkbox"/> 19. Silver Sponsor | \$1,000 – \$2,499 | \$ _____ |
| <input type="checkbox"/> 20. Bronze Sponsor | Up to \$999 | \$ _____ |
| <input type="checkbox"/> 21. Conference book ½ page ad | \$100 | \$ _____ |
| <input type="checkbox"/> 22. Conference book full page ad | \$200 | \$ _____ |
| <input type="checkbox"/> 23. Virtual Exhibitor | \$250 | \$ _____ |

Total: \$ _____

PAYMENT INFORMATION

- Check made payable to ASF
 Visa or MasterCard American Express Total amount enclosed or to be charged \$ _____

Name on Card _____ Signature _____

Billing Address (if different from above) _____

Card Number _____ Expiration Date _____

Please mail, fax or email this form to:

Sheila Wenger, 2013 ASF Conference Coordinator
4255 Westbrook Drive, Suite 219 • Aurora, IL 60504
800-432-6435 or 630-978-4245 • Fax: 630-978-7408 • www.angelman.org

2013 CONFERENCE PROGRAM AT-A-GLANCE

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Tuesday, July 23, 2013

7:45am – 8:45am	Scientific Symposium Breakfast – Registered Symposium Attendees Only
7:45am – 5:00pm	Scientific Registration Only
9:00am – 10:30am	ASF SCIENTIFIC SYMPOSIUM Marisa Bartolomei, PhD - University of Pennsylvania Ype Elgersma, PhD - Erasmus University Scott Dindot, PhD - Texas A & M Catherine Dulac, PhD - Harvard University Jon Huibregtse, PhD - University of Texas Jim Resnick, PhD - University of Florida Huda Zoghbi, MD - Baylor University
10:30am – 10:45am	Break
10:45am – 12:00pm	In session - The Scientific Symposium is intended for scientific, medical, research professionals and the Scientific Advisory Committee (SAC).
12:00pm – 1:25pm	Scientific Luncheon by Invitation Only
1:25pm – 2:30pm	In Session
2:00pm – 6:00pm	Practical Communication Strategies for Individuals with Angelman syndrome of All Ages – Mary-Louise Bertram
2:30pm – 2:45pm	Break
2:45pm – 4:25pm	In Session
4:30pm – 7:00pm	Scientific Reception by Invitation Only

Wednesday, July 24, 2013

7:45am – 8:45am	Scientific Symposium Breakfast – Registered Symposium Attendees Only	
8:00am – 6:00pm	Registration Hours	Opens at 2:00pm: Children's Awake & Play Room
9:00am – 2:50pm	211 Scientific Presentations - The Scientific Symposium is intended for scientific, medical, research professionals and the Scientific Advisory Committee (SAC)	Break: 10:30am – 10:40am Lunch: 12:00pm – 1:15pm
9:00am – 10:15am	222 First Timer's Session	
10:20am – 11:20am	221 Parent-to Parent – Deletion Positive 231 Parent-to-Parent – UBE3A 241 Parent-to-Parent – UPD, Mosaic, ID	
11:30am - 12:30pm	223 Just for Relative's Session 233 Just for Sibling's Session	Tatiana Bushey, Lesley McCullough-McCallister, Sydney Yost
12:40pm – 1:40pm	224 Just for Dad's Session 234 Just for Grandparents	Anthony Stein
1:50pm – 3:10pm	235 Just for Mom's Session	
2:50pm – 3:15pm	Break	
3:15pm – 4:30pm	Research Updates Panel/Awards Ceremony: Dr. Dan Harvey and Dr. Ben Philpot	
6:00pm – 8:30pm	Welcome Reception – Included in Full Registration, Child Registration, Care Provider Registration and Wednesday One-Day Registration	

Thursday, July 25, 2013

7:00am – 8:15am	State-by-State Continental Breakfast – Included in Full Registration, Child Registration, Care Provider Registration and Thursday One-Day Registration	
7:00am – 5:00pm	Registration Hours	
8:00am – 5:00pm	ASF Store Open	24 hours: Children's Awake & Play Room
8:30am – 9:30am	Keynote – Navigating the AS Behavior Modules	Dr. Jane Summers
9:00am – 3:00pm	Children's Activity: LegoLand	
9:40am – 10:40am	Keynote – Fostering Communication Skills in Individuals with AS	Dr. Stephen Calculator
10:40am – 10:55am	Break	
10:55am – 11:55am	311 Genetics 101	Dr. Charles Williams

2013 CONFERENCE PROGRAM AT-A-GLANCE

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	321 Seizures 101 Dr. Ron Thibert 331 341 ER Considerations Dr. Justin Grill
11:55am – 12:55pm	Lunch – on your own.
1:00pm – 2:00pm	312 Treatment of Seizures in AS Dr. Mark Nespeca 322 AS Clinics Update 332 Communication Mary-Louise Bertram 342 Sleep Issues Dr. Brett Kuhn
2:10pm – 3:10pm	313 Treatment of Seizures in AS Dr. Mark Nespeca 323 Diet Therapy Dr. Ron Thibert 333 Emerging Literacy Mary-Louise Bertram, Erin Sheldon 343 Sleep Issues Dr. Brett Kuhn
3:10pm – 3:25pm	Break
3:30pm – 4:30pm	314 LGIT: A Parent's Perspective Sybille Kraft-Bellamy 324 Diet Therapy Dr. Ron Thibert 334 AAC RJ Cooper 344 Medication Management of Challenging Behaviors Dr. Logan Wink
4:40pm – 6:15pm	317 Ask the Doctors – Seizures Dr. Ron Thibert, Dr. Mark Nespeca 327 Ask the Doctors – Communication Dr. Stephen Calculator, RJ Cooper, Mary-Louise Bertram 337 Ask the Doctors – Behavior Dr. Brett Kuhn, Dr. Jane Summers, Dr. Logan Wink

Friday, July 26, 2013

7:00am – 8:20am	Continental Breakfast – Included in Full Registration, Child Registration, Care Provider Registration and Friday One-Day Registration
7:00am – 4:00pm	Registration Hours
8:30am – 2:15pm	Children's Activity: Dolphins & Manatee Encounter
8:30am – 4:00pm	ASF Store Open Closes at 4:00 p.m. Children's Awake & Play Room
8:30am – 9:30am	411 Dadvocate Thomas Nurse 421 Keeping Your Marriage Strong Dr. Robert Dell 431 Inclusive Education for Students with AS Dr. Stephen Calculator 441 Navigating Residential Placement David Boyer
9:40am – 10:40am	412 iPad Essentials Erin Sheldon 422 Hippotherapy Katy Guardia 432 Tax Planning Jaret Vogel 442 Guardianship Jess Levins
10:40am – 10:50am	Break
11:00am – 12:00pm	413 Dreaming New Dreams Eliana Tardio 423 Medicaid Mary Anne Ehlert 433 Animal Assisted Therapy Randy Eady 443 Transitional IEP Thomas Nurse
12:30pm – 1:30pm	Lunch iPad Applications RJ Cooper
1:40pm – 2:40pm	414 Effective School Advocacy Erin Sheldon 424 What's the Big Idea Jill Fane 434 Potty Training Judith Coucouvanis 444 April the Artist Linda Cundy
2:50pm – 3:50pm	415 Speech Therapy 425 IEP Analysis Maggie Soucy 435 Potty Training Judith Coucouvanis 445 Microboards Ruthie-Marie Beckwith

GENERAL CONFERENCE REGISTRATION FORM

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FULL CONFERENCE – ADULT 18+

Name on Badge	Early Registration by 7/8/13	Late Registration after 7/8/13	
	\$240	\$275	\$
			\$
			\$
Full Conference Subtotal:			\$

ONE-DAY REGISTRATION – ADULT 18+

Name on Badge	Indicate Day of Attendance (W, Th, F)	Early Registration by 7/8/13	Late Registration after 7/8/13	
		\$180	\$200	\$
				\$
				\$
One-Day Registration Subtotal				\$

CHILD/ INDIVIDUAL WITH AS & CARE PROVIDER REGISTRATION (\$180 PER PERSON)

Include Signed Waiver with each Registration

Name on Badge	Has AS? Y or N	Age	T-Shirt Size	Early Registration by 7/8/13	Late Registration after 7/8/13	
				\$180	\$200	\$
						\$
						\$
Child/ Individual With AS & Care Provider Registration Subtotal						\$

MEAL PACKAGES

All meals are included in registration prices. This option is for those not registering for the Conference but would like to attend meals.

Name on Badge	Wednesday Night Reception, Breakfasts (Thursday & Friday) for Child/Individual with AS:	Wednesday Night Reception, Breakfasts (Thursday & Friday) for Adult:	
	\$50	\$70	\$
			\$
			\$
Meal Package Subtotal			\$

EXTRA TICKETS - WEDNESDAY EVENING WELCOME RECEPTION

Included in full Conference adult, child/individual with AS and care provider registrations and Wednesday one-day registrations.

Name on Badge	Child 0-17 years and Individuals with AS	Adult 18+	
	\$20	\$30	\$
			\$
			\$
Meal Package Subtotal			\$

GENERAL CONFERENCE REGISTRATION FORM

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MEAL OPTIONS AND T-SHIRT SIZES

To assist the ASF in their conference planning and meal projections, please indicate which meal functions each paid registrant will attend by checking all appropriate boxes. 2013 Conference logo t-shirts are included in Child/AS Individual & Care Provider Registrations ONLY. Additional t-shirts can be purchased below.

YS, YM, YL = \$8.00; S, M, L, XL = \$10.00; XXL = \$12.00; XXXL = \$15.00

Name	T-Shirt Size	Attending Wednesday Night Reception	Attending Thursday Breakfast	Attending Friday Breakfast	Dietary Restrictions	
						\$
						\$
						\$
						\$
						\$
						\$
T-Shirt Subtotal						\$
Grand Total						\$

Name _____ Email Address _____
 Address _____
 City _____ ST/Province _____ Zip/Postal Code _____
 Signature _____ Check# _____
 Card # _____ Exp. Date _____ Visa/MC/AMX _____

The Angelman Syndrome Foundation (ASF) is pleased to offer activities and programs specifically for children attending the ASF Conference. In addition to paying a registration fee for each child to attend the children's activities, ASF requires that a release form be signed and submitted by the parent or guardian for each child.

ASF Policy: All children attending any ASF program must be registered. All children under the age of 18 must be accompanied by an adult at all times. The parent or legal guardian must sign and submit a Child Release Form for each child registering to attend an ASF program. (Duplicate this form as needed.) ASF activities for which a form must be submitted include, but are not limited to, the following: the first time attendee orientation, receptions, all meal functions, meetings, educational sessions, trips, and all onsite and offsite activities.

Release Clause: As parent or guardian for the child listed below, I acknowledge that there may be risks associated with events and activities sponsored by ASF that could result in injury or illness to my child. In consideration of my child's participation in ASF events and activities at the ASF Conference, July 23 – July 26, 2013, and intending to be legally bound, I hereby waive, release and forever discharge any and all rights, actions, and claims which they or their heirs, executors or assigns may have against the Angelman Syndrome Foundation, its officers, directors, members, staff, volunteers, representatives, successors, assigns, and subcontractors including the hotel, rental supply companies and all other third party suppliers for death, injury, loss and any and all damages which I or my child may sustain and/or suffer in connection with my or my child's participation in this event. I understand that my child participates in these activities at his/her own risk and at my own risk.

My signature below also authorizes ASF, its employees, agents and subcontractors to obtain necessary emergency medical treatment for the child listed below.

Date _____
 Child's Name _____ Age _____
 City _____ ST/Province _____ Zip/Postal Code _____
 Print Parent/Legal Guardian's Name _____
 Signature _____ Relationship _____

Complete one form for each child registered for the conference. Duplicate this form as needed. Children's registrations will not be accepted without accompanying Child Release Form(s).

SCIENTIFIC SYMPOSIUM REGISTRATION

Championing Progress • July 23 – July 26, 2013
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SCIENTIFIC SYMPOSIUM - ADULT 18+

The Scientific Symposium is intended for scientific, medical, research professionals and the Scientific Advisory Committee (SAC). Parents should register using the general registration form and signing the scientific observer form.

Name on Badge	Early Registration by 7/8/13	Late Registration after 7/8/13	
	\$275	\$300	\$
			\$
Subtotal:			\$

SCIENTIFIC SYMPOSIUM - STUDENT

The Scientific Symposium is intended for scientific, medical, research professionals and the Scientific Advisory Committee (SAC). Parents should register using the general registration form and signing the scientific observer form.

Name on Badge	Registration	
	\$100	\$
		\$
Subtotal:		\$

FULL CONFERENCE – GENERAL SESSIONS JULY 24-26, 2013

Scientific Symposium Registration also includes attendance to any/all general Conference sessions. Please indicate attendance day(s):

Attendee	Attending All General Sessions	Wednesday, July 24	Thursday, July 25	Friday, July 26

EXTRA TICKETS - WEDNESDAY EVENING WELCOME RECEPTION

Included in full conference adult, child/AS individual & care provider registrations and Wednesday one-day registrations.

Name on Badge	Child 0-17 years & AS Individuals	Adult 18+	
	\$20	\$30	\$
			\$
Subtotal:			\$

MEAL OPTIONS AND T-SHIRT SIZES

To assist the ASF in their conference planning and meal projections, please indicate which meal functions each paid registrant will attend by checking all appropriate boxes. 2013 Conference logo t-shirts are included in Child/AS Individual & Care Provider Registrations ONLY. Additional t-shirts can be purchased below. YS, YM, YL = \$8.00; S, M, L, XL = \$10.00; XXL = \$12.00; XXXL = \$15.00

Name	T-Shirt Size	Attending Wednesday Night Reception	Attending Thursday Breakfast	Attending Friday Breakfast	Dietary Restrictions	
						\$
						\$
T-Shirt Subtotal						\$
Grand Total						\$

SCIENTIFIC SYMPOSIUM OBSERVER FORM

I understand that when observing the ASF Scientific Symposium I must stay in the room for the entire session and not leave in the middle of the session. I am not permitted to participate, only observe. Breakfast, lunch and break refreshments are included, but the scientific reception is NOT included for observers.

Name of Observer (please print)

Signature of Observer

Name _____ Email Address _____

Address _____

City _____ ST/Province _____ Zip/Postal Code _____

Signature _____ Check# _____

Card # _____ Exp. Date _____ Visa/MC/AMX _____

CONFERENCE INFORMATION

Championing Progress • July 23 – July 26, 2013

Walt Disney World Swan & Dolphin • Orlando, FL

Full Conference Registration Includes:

Participation in all general conference sessions, the Wednesday evening welcome reception, Thursday and Friday morning breakfasts, mid-morning breaks, afternoon refreshment breaks, all registration and conference materials and complimentary access to children's awake and play room. NOT INCLUDED: hotel and transportation costs, food and beverage other than stated above and optional group events.

Room reservations must be made directly with the Walt Disney World Swan & Dolphin

One-Day Registration Includes: A one-day fee includes all general conference sessions for chosen day, refreshments and activities held on that day (Optional group event not included in registration fee).

Child/AS Individual and Care Provider Registration Includes: Wednesday evening welcome reception, Thursday and Friday morning breakfasts, offsite activities Thursday and Friday, and complimentary access to children's awake and play room.

Meal Packages Include: Wednesday evening welcome reception, Thursday and Friday morning breakfasts.

Scientific Registration: Scientific Registration includes scientific sessions, meals and refreshment breaks on Tuesday and Wednesday. This registration option also includes sessions, meals and breaks as stated in the full (general) conference registration option on Wednesday through Friday of the conference.

Please note that Scientific Symposium sessions are intended for scientific, medical, research professionals and the Scientific Advisory Committee (SAC). If parents wish to attend you may register as an observer or as a symposium registrant. As an observer, you must stay in the room the entire session and not leave in the middle of the session. You will not be permitted to participate, only observe. Breakfast and break refreshments are included, but the scientific lunch and reception is NOT included for observers. Children are not allowed in the Scientific Symposium sessions.

Note: Only attendees registered for Full Conference, One-Day or Scientific

Symposium will receive a conference program book and conference bag. Additional books or bags may be purchased at the end of the conference, while supplies last.

Confirmation: Conference confirmations will be emailed or mailed out within two weeks of receiving your completed registration and payment. Registrations will not be processed without payment.

Badge & Meal Policy: Attendee badges must be worn at all ASF functions. No one will be allowed access to any functions during the conference without a badge and/or meal ticket. All badges will be under the Family Name as you list on your form.

Just for Siblings, Grandparents & Relatives Sessions: All non-registered siblings, grandparents and relatives are allowed access to these sessions free of charge. Please indicate your attendance for these sessions by including your name on the reservation form and indicating the session you will be attending next to your name.

Deadlines: Save on registration fees by registering before the deadline of July 8, 2013. See registration form on page 8 - 10 for fee schedule. Registrations will be accepted at the office until July 18, 2013. After July 18, 2013 individuals should register onsite during regular registration hours.

Cancellation Policy: Should you need to cancel your conference registration, a letter must be sent to the ASF office requesting a refund. This letter must be received by July 8, 2013 to receive a full refund less a \$50.00 processing fee. No refunds will be issued after July 8, 2013.

If ASF cannot hold the conference due to acts of God, war, terrorism, government regulation, disaster, strikes, civil disorder or curtailment of transportation facilitating other emergencies making it inadvisable, illegal or impossible to provide the facilities or to hold the meeting, each prepaid registrant will receive a copy of conference handouts and any other materials that would have been distributed. Fixed conference expenses will be paid from the pre-registration funds. Remaining

funds will be refunded to pre-registrants. ASF is not responsible for any other costs incurred by registrants in connection with the conference.

Awake and Play Room: A special room will be available 24-hours a day with toys and videos for individuals with Angelman syndrome and their siblings. Please note that a parent or care provider must accompany children while using the Awake and Play Room.

Children's Programs On Thursday and Friday special events will be planned for children and their care providers. While you are in sessions on Thursday and Friday children will be off on special activities. ASF does not provide care providers for any activities. All AS individuals must have an adult (18+) care provider with them and all children under 16 must be accompanied by an adult. Lunch will be provided during the Thursday and Friday activities.

Thursday's activities include a day at LEGOLAND. Shuttles will leave the hotel at 9:00 a.m. Attendees will get to enjoy the park at their leisure until 2:20 p.m. when they board the shuttles back to the hotel. An exclusive BBQ lunch is included. Friday morning attendees will board the shuttles at 8:30 a.m. and be transported to the Banana River. Here attendees will transfer to a covered pontoon boat and take a wildlife cruise to view the dolphins and manatees. A picnic lunch is included. The pontoon boats are wheel- chair accessible, but participants must be able to step onto the boat from the dock. Participants will return to the hotel around 2:15 p.m.

T-Shirts: 2013 Conference t-shirts will be included with Children & Care Provider Registration. Additional t-shirts can be pre-ordered by June 28, 2013. If you would like to order a t-shirt, please indicate quantity on your conference registration form on page 8 and/or 9.
YS, YM, YL = \$8
S, M, L, XL = \$10
XXL = \$12
XXXL = \$15

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Special Thoughts: On a tender note, we must remind you that the conference sessions are for adults. It is meant as a fast-paced getaway from the usual routine of care giving. Considerable time and energy goes into planning a program that will be useful and well organized, with an allowance of ample free time to network and at a cost that is affordable. It is an exhilarating, yet, exhausting experience and we want you to get the most from it.

Children will not be allowed in conference sessions. This policy will be strictly enforced.

If two adults plan on attending the conference with their individual with Angelman syndrome and do not have an adult care provider, one adult will miss the opportunity to attend sessions. ALL children under 16 must be accompanied by an adult at all times. Session rooms will be monitored and any child(ren) in sessions will be asked to leave.

Attire: All activities are casual. Dress for comfort. Meeting room temperatures tend to run on the cool side so you might consider bringing a jacket or sweater.

Official Conference Language: The official language of the conference is English.

Release of Liability and Use of Photographs: By registering for the ASF Conference, it is understood that all attendees hereby waive, release and forever discharge any and all rights, actions, and claims which they or their heirs, executors, or assigns may have against the Angelman Syndrome Foundation and its officers, directors, members, staff, volunteers, representatives, successors, and assigns for death, injury, loss and any and all damages which the attendee or attendee's child may sustain and/or suffer in connection with their or their child's participation in this event. It is further understood that by registering for the conference, attendees grant permission for the sponsors of this event to use their or their child's name and photograph, and any quotations from the attendees, in legitimate accounts and promotion for this event. Attendees will receive no compensation for the use of their or their child's name, photograph or quotation.

Audio CD & CD-ROM Sales: CDs, CD-ROMs and an on-line digital library of most sessions may be purchased throughout

the conference shortly after they are recorded. They may also be ordered after the conference directly through the audio company or via a link to the audio company on the ASF website.

Special Needs: If you have any special needs as addressed by the Americans with Disabilities Act, please notify the ASF office at least three weeks prior to the conference. It is important also to notify the hotel of these needs when making your reservation. Special dietary requests must be made in writing at least one week prior to the conference.

Views and Opinions: The views and opinions expressed by the speakers and virtual exhibitors are their own and do not necessarily represent those of ASF. ASF disclaims any responsibility for the use and application of the information presented at this conference.

Weather: Expect day-time highs of about 92°F (31°C) and night-time lows of about 74°F (19°C). July is the time for clear and sunny skies with sudden, heavy thunderstorms occurring almost every afternoon.

Electricity: The electricity used in Orlando is standard electricity, which is 110 volts. European appliances brought here will require a voltage transformer.

HOTEL

Walt Disney World Swan
1500 EPCOT Resorts Blvd.
Lake Buena Vista, FL 32830
407-934-4000
888-828-8850
www.swandolphin.com

Accommodations: Special guestroom pricing for ASF attendees:

Single/Double Occupancy - \$129.00 Room rate is quoted exclusive of applicable state and local taxes, which are currently 12.5%. Extra person charge is \$25 per night. Children under 18 years of age may stay for free in their parents' room using existing bedding. The cut-off date to request a reservation at the group rate is Friday, June 21, 2013 at 5:00 p.m. ET.

Cancellation Policy: If you need to cancel your hotel room, you must cancel at least five days prior to arrival to avoid penalties. If you cancel your room within five days prior to arrival, one night room & tax charge applies.

Service and Facilities:

- Two Business Centers
- 24-hour front desk
- 24-hour convenience store/cafeteria
- Coin operated launderette
- Room service
- Safe deposit boxes
- Game Room
- Mandara Spa - offering exotic spa services as well as a full-service hair and nail salon
- Car rental service (National & Alamo)
- Complimentary scheduled transportation to all Walt Disney World Theme Parks & attractions
- Two on-site Disney ticket desks
- Speciality Shops
- 24-hour bellstand
- Pets are not allowed. Exceptions are made for assistive working animals.

Resort Service Package: There is a mandatory Resort Services Package fee of \$12.00 per room per day that was negotiated into the standard room rate. This package includes unlimited local calls and 800 number calls up to sixty minutes, 20 minutes of domestic long distance per day, complimentary bottled water replenished daily, high-speed internet access and unlimited admission to the fitness centers.

Restaurants and Bars:

Todd English's bluezoo - Enjoy coastal cuisine from Celebrity Chef Todd English, incorporating an innovative selection of fresh seafood in an energetic and vibrant atmosphere. AAA Four Diamond Award recipient and multi-award winner of Wine Spectator's Award of Excellence. Open for dinner.

Shula's Steak House - Shula's serves the best beef money can buy, The SHULA CUT®, in addition to the freshest seafood, and 3-5 lb. live Maine lobsters. Critic's choice for Orlando's Best High-End Steak House and multi-award winner of Wine Spectator's Award of Excellence. Open for dinner.

Il Mulino New York Trattoria - Traditional Italian cuisine from the Abruzzi region of Italy, served in a dynamic rustic trattoria. Features a diverse offering of exciting and bountifully presented dishes, prepared from original Italian recipes. Open for dinner.

Fresh Mediterranean Market - Savor fresh, made-to-order menu items from

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our Mediterranean-style market. Open for breakfast and lunch.

The Fountain - Crisp salads, custom grilled burgers, and a delectable array of sandwiches and desserts. Take away homemade or soft serve ice cream. Open for lunch and dinner.

Cabana Bar AND Beach Club - Sleek and contemporary, with a hint of South Beach style, this is the perfect place for lunch or dinner. Then transition into evening with cocktails at the illuminated bar. Open seasonally.

Splash Terrace - Lunch, snacks, and ice cream, just steps from the pool and white sand beach. Outdoor seating with table service. Open seasonally.

Garden Grove - Disney characters featured nightly for dinner buffets and breakfast on Saturdays and Sundays. Open for breakfast, lunch and dinner. Characters and times subject to change without notice. Characters not featured during lunch.

Picabu - A curious gallery of evocative art and America's favorite foods. Self-service dining and sundries, open 24 hours a day.

Splash GRILL - Lunch, snacks, and ice cream, just steps from the pool and white sand beach. Self-service restaurant with indoor seating. Open seasonally.

JAVA BAR - An inviting and relaxed setting to enjoy espresso, cappuccino, or a variety of coffees, along with a selection of freshly prepared pastries. Also serving an assortment of other refreshing beverages.

Recreational Facilities:

Fitness center is available for guests 24-hours per day featuring state-of-the-art equipment.

Pool: The pool is open from 9:00am - 9:00pm

- Grotto Pool with water slide
- Two lap pools
- Spring pool
- Four whirlpools
- Kiddie pool

Points of Interest:

- Disney's Magic Kingdom®
- Disney's Animal Kingdom®
- Disney's Hollywood Studios™
- Disney's Epcot®
- Disney's Typhoon Lagoon® Water Park
- Downtown Disney® Marketplace
- Downtown Disney® Westside
- SeaWorld

- Universal Studios and Islands of Adventure
- Kennedy Space Center
- Daytona Beach
- Cocoa Beach
- Clearwater Beach
- Orlando Premium Outlets
- Mall of Millenia
- Prime Outlets International

MEDICAL FACILITIES

Florida Hospital Orlando
601 E. Rollins St., Orlando, FL 32803
407-303-5600

Winnie Palmer Hosp. for Women & Babies
88 W. Miller St., Orlando, FL 32806
321-843-9792

Orlando Regional Medical Center
1414 Kuhl Ave., Orlando, FL 32806
321-841-5111

Arnold Palmer Hospital for Children
92 W. Miller St., Orlando, FL 32806
407-649-9111

Nemours
13535 Nemours Pkwy., Orlando, FL 32827
407-567-4000

TRANSPORTATION

Airlines: If you are traveling by air, American Airlines is the official 2013 conference carrier. You may contact American Airlines by phone at 800-433-1790. A \$25.00 fee for paper tickets issued via phone reservations will be added to the cost of each ticket. Flight arrangements may also be made via the web at www.aa.com. Use code #9273BS for a 5% discount.

Airports and Airport Transportation:

Orlando (McCoy) International Airport (MCO) - 407-825-2001. For more information regarding flights, arrival and departure times, and weather updates, please contact your airlines directly.

The Walt Disney World Swan & Dolphin does not provide complimentary airport shuttle service to and from the airport. The hotel is approximately 20 miles from MCO Airport.

Ground Transportation: Super Shuttle is available and offers a 10% discount off any round trip reservation made and paid online. Use discount code DQU6M when booking

your reservation online at:
<http://www.supershuttle.com>.

Mears Transportation is also available and offers \$4.00 off each round-trip ticket price. Visit <https://secure.mearstransportation.com/Default.asp?referrer=431767079> or call 407-423-5566 for rates and reservations. It is approximately \$34.00 roundtrip and \$21.00 one-way for adults; \$27.00 roundtrip and \$17.00 one-way for children (ages 4 - 11).

Rental Cars: Avis is offering a discount to anyone interested in renting a car while in Orlando. Please use code D087974 when making your reservation.

The group discount number is designed to shop the best available rate, includes unlimited mileage and is available seven days before to seven days after the event. Reservations should be made by calling Avis directly at 800-331-1600 or by visiting: www.avis.com.

VIRTUAL EXHIBITORS AND SPONSORS

Virtual Exhibitors: Companies have been invited to participate as virtual exhibitors for the 2013 conference. Virtual exhibitors will provide information regarding their products and services. This information will be included with your conference registration materials.

Sponsors: The ASF conference relies on sponsors and contributors to help offset conference expenses and provide scholarship opportunities. This year we are seeking over \$35,000 in sponsorship income as a means to keep individual registration fees affordable. If you or someone you know is interested in sponsorship opportunities, contact the ASF office at 800-432-6435.

Extended Magic Hours: Guests at the Walt Disney World Swan & Dolphin can participate in extended magic hours at select Disney® parks. Extended Magic Hours are subject to change.

There are also special conference rates on tickets to select parks if you visit after 2:00pm or 4:00pm. Visit the ASF website at www.angelman.org for a link to purchase these discounted tickets.

We look forward to seeing you in Orlando!

SCHOLARSHIP APPLICATION

Championing Progress • July 23 – July 26, 2013

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The Angelman Syndrome Foundation will be offering a limited number of scholarships to aid families who may not otherwise be able to attend. Scholarship awards include conference registration and up to four (4) nights hotel accommodations at the Walt Disney World Swan & Dolphin. Scholarships will be awarded on a financial need basis, and funds are available up to \$1,000. Conference scholarships are not cash awards and no money or funds are exchanged. **All completed applications must be received at the ASF office no later than May 9, 2013. Applications received after May 9, 2013 will not be considered.** All information provided will be held strictly confidential.

- I, _____ (applicant's name – please print) understand that by submitting this scholarship application I / my family will be fairly considered for scholarship funding.
- Further, by submitting this application I understand that I / my family will incur additional expenses which are my / my family's responsibility.
- I / my family understand that all children, under the age of 18, and all individuals with Angelman syndrome, must be in the presence of a care provider throughout the conference. A care provider must be at least 18 years of age.
- I / my family understand that by accepting this scholarship, full-conference and one-day registered attendees are expected to attend sessions throughout the conference and / or on the selected one-day of sessions.
- Finally, by submitting this scholarship application, I / my family understand that I / we are declaring that we accept the scholarship award, we will stay at the Walt Disney World Swan & Dolphin and we must attend the entire 2013 ASF Biennial Conference in Orlando, FL on July 24 – 26, 2013.

Name of Applicant (Please Print)

Signature of Applicant

APPLICANT INFORMATION

Date: ____/____/____
MM DD YYYY

Last Name: _____

First Name: _____

Address: _____

City: _____ ST: _____ Zip: _____

Phone: _____

Email: _____

I **do / do not** have a child with AS (circle one)

Previously attended conference(s)? Yes No (circle one)

If Yes, please indicate conferences attended: '91 '93 '95 '97
'99 '00 '01 '03 '05 '07 '09 '11 (circle all that apply)

I **have / have not** applied for scholarship funding from
ASF previously (circle one)

I **have / have not** received scholarship funding from
ASF previously (circle one)

PLEASE ATTACH A COPY OF YOUR MOST RECENT IRS 1040 OR APPLICABLE TAX RETURN. _____

Written Response

Please attach to this form your written statement of no more than 250 words. Any and all information over and above 250 words will not be considered. You can also email your written statement to Sheila Wenger at swenger@angelman.org. Your written statement should include:

- A. Explain the benefits you will derive from attending the conference
- B. Describe how an ASF Conference Scholarship will lessen the financial burden on you / your family and assist you / your family in attending the 2013 conference. Please be specific and succinct.

SCHOLARSHIP APPLICATION

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Please indicate the number of people that this scholarship will apply to:

Adults: 1 2 3 (circle one)

Children: 1 2 3 (circle one)

Adult 1: _____ Relationship to person completing this form: _____

Adult 2: _____ Relationship to person completing this form: _____

Adult 3: _____ Relationship to person completing this form: _____

Child 1: _____ Relationship to person completing this form: _____

Child 2: _____ Relationship to person completing this form: _____

Child 3: _____ Relationship to person completing this form: _____

Budget Calculations

# Adult Full conference Registration	_____	X \$240	=	\$ _____
# Scientific Symposium Registration	_____	X \$275	=	\$ _____
# Scientific Symposium Observer	_____	X \$150	=	\$ _____
# Care Provider Registration	_____	X \$180	=	\$ _____
# Child/Individual with AS Registration	_____	X \$180	=	\$ _____
# Care Provider Reception Only	_____	X \$25	=	\$ _____
# One-Day Registration	_____	X \$15	=	\$ _____
#Nights Lodging plus tax @ WDW Swan (up to 4 nights will be considered)	_____	X \$143.13	=	\$ _____
# Child/Individual with AS Meal Packages	_____	X \$50	=	\$ _____
# Care Provider meal Packages	_____	X \$70	=	\$ _____
TOTAL				\$ _____

(Only actual amount of registrations and up to four nights plus tax at the WDW Swan & Dolphin, will be considered for a scholarship award up to \$1,000. Please contact Sheila Wenger (800-432-6435) or swenger@angelman.org if you have questions regarding the award amounts. Reception and meal packages are included in full registration amounts, only include these options if not registering child/individual with AS or care provider for conference, but would like them to attend meals.)

Financial Need

2012 Gross Annual Income: \$ _____

2012 medical express not covered by insurance: \$ _____

Total Number of Adult Individuals residing
within your home in 2012: _____

Total number of Dependent Individuals
residing within your home in 2012: _____

Have you applied for and / or received other funding
for the 2012 ASF Conference? Yes / No

If yes, indicate amount: \$ _____

Source of funding: _____

I certify that the information presented on this application is accurate and truthful, to the best of my knowledge. Failure to provide accurate and truthful information will result in my application being disqualified from consideration.

Name of Applicant (Please Print)

Signature of Applicant

Return application to:

ASF Conference Scholarship, Attn: Sheila Wenger • 4255 Westbrook Drive, Suite 219, Aurora, IL 60504
Fax: 630-978-7408 • Email: swenger@angelman.org

2013 CONFERENCE SPONSORS

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Thank you to our 2013 Conference Sponsors. We appreciate your generous support!



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Beverly & Steven Thomas
Mitch & JoAnne Thorsen
Gerald Vanderwal
Sheila Wenger
Al & Nancy Zatarga
Dan & Cindy Zatarga
Minnie Zatarga
Julie & Mitch Zimmer
Roya Zolnoor



CHAMPIONING PROGRESS

BIENNIAL CONFERENCE AND SCIENTIFIC SYMPOSIUM